

Programs for the Handicapped

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Revisions to 504 Guidelines**

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Address editorial and subscription inquiries to:

Programs for the Handicapped
CLEARINGHOUSE ON THE HANDICAPPED
Office of Information and Resources for the Handicapped
Room 3119 Switzer Bldg.
Washington, D.C. 20202
Telephone: (202) 245-0080

Administration Decides Against Revisions to 504 Guidelines

Vice President George Bush has announced that the Department of Justice and the Presidential Task Force on Regulatory Review, of which he is chairman, have concluded their review of Section 504 coordination guidelines under the Rehabilitation Act of 1973, and have decided not to issue a revised set of guidelines.

In a March 21 letter to Rep. Lowell Weicker (R-CT), chairman of the House Subcommittee on the Handicapped (published in the Congressional Record March 22), Vice President Bush said, "This decision brings to a close a lengthy regulatory review process during which the Administration examined the existing regulatory structure under Section 504, studied recent judicial precedents and talked extensively with Members of Congress and of the handicapped community. Especially important were the personal views and experience of those most directly affected by these regulations. The comments of handicapped individuals, as well as their families, provided an invaluable insight into the impact of the 504 guidelines.

"A full evaluation of all the information brought to bear

on this subject prompted the conclusion that extensive change of the existing 504 coordination regulations was not required," Bush continued, "and that with respect to those few areas where clarification might be desirable, the courts are currently providing useful guidance and can be expected to continue to do so in the future. In these circumstances, the Administration has decided not to proceed with its planned issuance of a revised set of proposed coordination guidelines."

Bush thanked Weicker for his personal participation in the review process, and informed him that his commitment to disabled citizens "is fully shared by this Administration."

After reading the letter into the March 22 Congressional Record, Weicker called it "a great relief to disabled Americans." He said, "Section 504 of the Rehabilitation Act is a cornerstone in the construction of equal rights for the disabled. It is a cornerstone to be built upon, and I can assure my colleagues that the Subcommittee on the Handicapped intends to continue to do just that."

'Jobs Bill' Boosts Handicapped Programs

The President signed a "Jobs Bill" into law on March 24 which affects several programs of benefit to handicapped individuals. Additional FY 1983 monies were awarded for architectural barrier removal in the schools, the projects with industry program, and the block grant programs for maternal and child health; alcohol, drug abuse, and mental health; and Title XX social services.

The full title of Public Law 98-8 is: "Emergency Jobs Appropriations: Making appropriations to provide productive employment for hundreds of thousands of jobless Americans, to hasten or initiate federal projects and construction of lasting value to the Nation and its citizens and to provide humanitarian assistance to the indigent for Fiscal Year 1983, and for other purposes."

Under the Department of Education, the law provides \$40,000,000 for architectural barrier removal, to help schools comply with the access requirements for the handicapped that are currently mandated by law. The appropriation will be administered by Special Education Programs, Office of Special Education and Rehabilitative Services (OSERS). The Secretary is presently considering the Department's options for awarding the funds and a decision is expected soon.

projects with industry program (PWI), to train approximately 5,000 handicapped individuals in meaningful and rewarding jobs. The PWI program is administered by the Rehabilitation Services Administration, OSERS.

Handicapped individuals are included among those who receive benefits from the maternal and child health block grant program, which received an additional \$105,000,000. All the States except nine have submitted their letters of assurance (that they will comply with the guidelines for the use of the funds), and have received their share of the additional appropriations granted the program under P.L. 98-8. The Bureau of Health Care Delivery Assistance in the Department of Health and Human Services (HHS) expects the other letters to arrive shortly.

Other programs administered by HHS which received additional appropriations are the alcohol, drug abuse, and mental health block grant, \$30,000,000; and the Title XX, social services block grant program, \$225,000,000.

These appropriations were part of the comprehensive "Jobs Bill" package, which also included funds for several programs of interest under the Department of Labor including \$32,400,000 for the Job Corps and



President and Mrs. Reagan with the Rossow family and their adopted handicapped children.

President Reagan Forms Working Group On Handicapped Policy

President Reagan announced April 5 the establishment of a Working Group on Handicapped Policy under the Cabinet Council on Human Resources. The working group will examine policy administered by the various agencies that have jurisdiction over programs that concern disabled citizens.

The President expressed his desire that the working group fashion policy toward the handicapped in ways that will:

- encourage care for the handicapped within the context of the family and school;
- promote integration of the handicapped into society, schools and the workplace; and
- foster independence and dignity in the lives of handicapped persons.

The announcement coincided with a meeting the President arranged at the White House with Rachel and Carl Rossow of Ellington, Connecticut, who have three children of their own and have adopted 11 severely handicapped children. Deputy Press Secretary Larry Speaks said the Rossow's experience is a major example of what individuals can do to help the handicapped.

capped Policy was held on April 14 to set the groundwork for future action. Bob Sweet of the White House Office of Policy Development chairs the working group. He reports that, in developing recommendations for positive change, the working group invites any input of innovative ideas from the private sector.

Address all correspondence to: Bob Sweet, Senior Staff Member, Office of Policy Development, The White House, Washington, DC 20500.

HHS To Appeal 'Baby Doe' Ruling

Secretary of Health and Human Services (HHS) Margaret M. Heckler announced April 14 that the agency intends to file an immediate appeal of U.S. District Court Judge Gerhard A. Gesell's ruling that declared invalid HHS interim final regulations that protect handicapped infants from being denied health care.

The regulations, which became effective March 22, required each recipient of federal funds who provides health care services to infants to post and keep posted in a conspicuous place in delivery, pediatric and maternity wards and nurseries a notice stating that "discriminatory failure to feed and care for handicapped infants in this facility is prohibited by federal law." The regula-

HHS Moves to Improve Board and Care

In response to a number of reports of abuse and neglect in board and care homes, the Department of Health and Human Services has instituted a department-wide program to improve state and local administration of such facilities.

Since the 1976 Keys Amendment to the Social Security Act, states have been required to establish and enforce standards for any category of institutions, foster homes, or group living arrangements in which the state determines that a significant number of Supplemental Security Income (SSI) recipients reside, or are likely to reside. The Federal regulations interpreted the amendment to cover all residential facilities which provide both room and board and continuous protective oversight to residents—more commonly known as board and care homes.

But Federal enforcement of the Keys Amendment has been perfunctory. To date, not one single violation of the standards has been reported.

In the meantime, the intention of the Keys Amendment—to encourage the development of board and care homes—has been successful. The number of residents of these facilities has far outpaced the states' ability to enforce adequate standards. Chief among the reasons for this failure are uncertainty over standards, inadequate funding and resources, no central agency responsible for standards and enforcement, and difficulty in locating board and residences.

And, since most residents of board and care homes are poor, and either disabled or aged, they are often unable to vacate an undesirable residence or protect themselves from abuse. They are dependent upon the skills and intentions of the board and care operators and the protective regulations of state and local governments.

In April 1982, the Inspector General's Office issued a report summarizing HHS's role in governing board and care facilities under the Keys Amendment, and set forth a plan of action subsequently adopted by Secretary Schweiker.

Under these guidelines, HHS has initiated a number of activities. The initial step was the formation of the Board and Care Coordinating Unit (BCCU) which is located in the Administration on Developmental Disabilities in the Office of Human Development Services.

Fire protection improvement is a high priority. The BCCU awarded two research grants to meet this need. A \$390,000 grant was made to the Center for Fire Research of the National Bureau of Standards to complete a Fire Safety Evaluation System (FSES) for board and

Safety Technology Division, National Bureau of Standards, Building 224, Room A363, Washington, D.C. 20234.

A second grant aimed toward fire protection was made to the National Fire Protection Association to conduct six seminars later this year on fire safety in adult boarding homes. The seminars will include participants from state and local regulatory agencies, elected officials, representatives of the residents, and boarding home operators and managers. Information will also be available on the newly developed FSES as well as methods of preventing fires. For further information write: Austin R. Sennett, NPPA, Batteymarch Park, Quincy, Massachusetts 02269.

In answer to the need for state guidelines, a Model Statutory Guidelines grant was awarded to the American Bar Association to develop and disseminate model state statutory guidelines encouraging the growth of board and care facilities, but averting abuse of residents. For further information write: Jane Beyer, ABA, Commission on Legal Problems of the Elderly, 1800 M Street, N.W., Washington, D.C. 20036.

A management information system will be developed by the New Jersey Department of Community Affairs, Bureau of Rooming and Boarding House Standards through a grant from BCCU. This system will provide a profile of rooming and boarding homes, operators and residents, schedule and monitor the inspection of board and care, and share information about rooming and boarding homes among agencies and concerned organizations through an Interagency Information Sharing System. For further information write: Mary Ellen Marino, Project Director, New Jersey Department of Community Affairs, Division of Rooming and Boarding House Standards, 363 W. State Street, Trenton, New Jersey 08625.

For more information on the activities of the Board and Care Coordinating Unit contact: Department of Health and Human Services, Administration on Developmental Disabilities, Board and Care Coordinating Unit, Room 348F Hubert Humphrey Bldg., 200 Independence Ave., S.W. Washington, D.C. 20201. Tel.: (202) 245-2910.

Study Assesses Services To Deaf-Blind Population

While deaf-blind people in the U.S. have made substantial educational gains in recent years, there still remain large areas of unmet or inadequately met needs, according to a year-long study jointly commissioned by the Department of Education's Special Education Programs and the Rehabilitation Services Administration.

The study, conducted by Rehabilitation and Education Experts, Inc. (REDEX), analyzed services by the number and characteristics of deaf-blind people, and included interviews with service providers, parents, deaf-blind adults, and government planners. All groups expressed varying degrees of concern about future funding and the adequacy of their facilities and staff to reach the growing population of deaf-blind persons and make them employable.

The study estimates the overall deaf-blind population at 734,275—much larger than previous estimates. It breaks down that figure as follows: profoundly deaf-blind, 41,859; deaf and severely visually impaired, 25,481; blind and severely hearing impaired, 357,818; and severely hearing and visually impaired, 309,117.

Taking into account the data from the surveys conducted and from reviews of pertinent literature, the project staff make the following suggestions for policies to improve services for deaf-blind persons:

- The Federal Government should assume the responsibility for annually determining the size and characteristics of the deaf-blind population.
- A continued federal presence is desirable in the education of deaf-blind children and youth.
- Encourage states to coordinate deaf-blind services at a decision-making level within their hierarchy of social services.
- Programs for deaf-blind children's parents should be established to provide them with education and respite care, two areas now seriously lacking.
- Every state needs to establish and maintain vision and hearing conservation programs, especially for persons who already have sensory impairments.
- A federal program of job development and job placement is urgently needed to supplement the efforts of State Vocational Rehabilitation agencies and Commissions for the Blind.
- Increased attention should be given to developing independent-living and alternate-living programs for deaf-blind adults.
- Research efforts must be funded to identify, invent, and evaluate new methods for overcoming the disadvantages of deaf-blindness.
- Federal support to recreational programs and services for deaf-blind persons should be increased.
- The nature of the deaf-blind population demands that a concerted effort be made to provide elder care.
- The assistance of deaf-blind consumers should be

sought in planning all programs specifically directed at serving them.

- Extend educational support for deaf-blind students from the present upper-age limit of 21 years up to 25 years of age.

A copy of the report can be obtained from Rodney Pelton, Director of Evaluation, Rehabilitation Services Administration, Switzer Building, Room 3532, 330 C St., S.W., Washington, D.C. 20202.

PCEH Recognizes Outstanding Achievements

The President's Committee on Employment of the Handicapped (PCEH) held its Annual Conference on May 4-6 at the Washington Hilton Hotel in Washington, D.C. During the Conference, a number of awards were presented recognizing the achievement of individuals from around the country in the area of services and programs for handicapped individuals.

Patricia Just Long, a producer-announcer with the South Carolina Educational Radio Network (SC ERN) in Columbia, was presented the "Handicapped American of the Year" award on May 5. Mrs. Long received the President's Trophy, the highest award for disabled people, at the opening session of the conference. Mrs. Long, who has been paralyzed since contracting polio when she was four years old, received the award both for her drive, determination and enterprise in overcoming her disability, and for her leadership in the equal rights movement of disabled people. At SC ERN she is responsible for producing such shows as "Mosaics," a radio magazine program featuring economic reports, sports, personalities, and human interest stories.

Five high school seniors were named national winners of the 1983 National Journalism Contest. The theme for this year's contest was "Independence for Disabled People through Technology." Harold Russell, Committee Chairman for PCEH, noted that "these young people showed a flair for good writing combined with solid reporting. Considering the difficulty of this year's theme, this was indeed a unique combination."

The five national winners, along with 24 state winners and one from Puerto Rico were invited to attend the PCEH Conference and received expense-paid trips provided by the AFL-CIO State Councils. The first place winner was Kathleen Reid, a student at the Spring Valley High School, Columbia, South Carolina, who described how a young man with a hearing impairment utilized computer technology to help him communicate

(See PCEH, page 20)

NIHR Hosts Conference On Parent/Child Interaction

By Inez Marie Fitzgerald

A group of researchers involved in the study of the interactions of parents and their handicapped children and intervention strategies met recently in Washington, D.C. at the invitation of the National Institute of Handicapped Research (NIHR) to develop research priorities for the Institute.

A series of presentations on key issues served to highlight research needs and to stimulate discussion leading to a group consensus on areas where further research is most urgently needed. Participants grappled with the complex net of sociological and psychological variables affecting the handicapped child and the family, in an effort to isolate factors which contribute to the development of the child.

Dr. Ann Turnbull, Kansas Research and Training Center on Independent Living, University of Kansas, pointed out the necessity of looking at the family as a system, with each interpersonal relationship affected by the others. The goals of family members interrelate, and at times work against each other. For example, the goals of developing competency in the child and reducing stress in the family contradict each other, since it can be very stressful for parents to work with a child to develop a particular skill. Recent emphasis on involving parents in the education of their handicapped children necessarily impacts on their relationships with their other children and with each other. For this reason, the environment that is least restrictive for the child may be most restrictive for the parents. It is partly for this reason that some parents resist deinstitutionalization.

Parents have, in addition to goals, various ideologies that affect the way they raise their handicapped children. These ideologies embody parents' preferences for overriding values such as independence, maximum security, socialization, lack of stigma through competence, and others which determine what type of future they are working toward for their handicapped child. Professionals working with parents should help them make their goals and ideologies explicit and to introduce interventions which support those goals and values. Dr. Turnbull stressed the need for theoretical models building in variables to account for interpersonal relationships; for longitudinal research to study family adaptation and the success of interventions; and for a focus on family strengths, as opposed to family deficits, in working out intervention strategies.

In discussing her research on high risk infants of disadvantaged mothers, Dr. Jeanne Brooks-Gunn of the Educational Testing Service reported that mothers can be classified in three groups: those who can cope on their own, those who can cope with some help, and those

tance. Devoting personnel and resources to providing services for the latter group will not yield great improvements in maternal care of infants. Targeting services to the middle group, on the other hand, will result in improved maternal behavior and infant well-being.

Conference participants realized the magnitude of the ethical issues involved, and the importance of developing criteria for resource allocation. There was a consensus that decisions could not be made solely on the basis of probable results expected. It was pointed out that programs for handicapped high risk infants and their families should be well structured and of medium to high intensity.

Some related considerations on resource allocation surfaced during the discussion on the cost-effectiveness of early intervention programs, initiated by Lawrence J. Schweinhart's presentation. Mr. Schweinhart, who is associated with the High/Scope Educational Research Foundation in Ypsilanti, Michigan, reported on research in which he has been involved since 1975, a unique longitudinal study on the cost-effectiveness of early intervention.

In this study 123 black children with "borderline" IQ's (from 70 to 85) from economically disadvantaged families were followed, from age 3 or 4 to age 19. Some of the children attended a preschool program for two years; others, for one year. The control group did not receive preschool education. The results of the study are compelling: the children who attended preschool required fewer years of special education, and were more likely to graduate from high school (or earn an equivalency diploma), to receive postsecondary training, and to enter the job market, and less likely to receive certain types of welfare or to have a police record. They also scored higher than the control group on a functional competency test. It is interesting to note that the children who received only one year of preschool education did as well as the children who went to preschool for two years.

In terms of cost-effectiveness, the study results point toward the need for more early education programs for disadvantaged children, to reduce the number of children requiring special education and the number of young adults receiving welfare payments. The cost of the program was \$2,992 per child per year (amounts refer to 1979 dollars). Among the economic benefits are \$3,353 per child saved in special education costs and \$10,798 in increased lifetime earnings. There are also many intangible benefits associated with a better education and greater social responsibility.

While conference participants agreed that there is a need to channel funds into preschool programs, they

cies would permit large expenditures for programs which will not show a return on the investment for some years. Again, the question of targeting of resources arose. The children served in the preschool study were not seriously handicapped. Very often programs are designed to reach those who are the worst off, leaving out mildly handicapped children who are most likely to show improvements as a result of services.

In drawing up a list of priorities recommended for NIHR research efforts, conference participants underlined the need for comprehensive studies on the cost-effectiveness of programs for handicapped children, especially the learning disabled, mentally impaired and speech impaired, and for longitudinal studies. Other priorities include the following: 1) investigation of interactions between parents and handicapped children, in particular to identify positive behaviors and to examine affective/emotional outcomes; 2) examination of changes in and interactions between child, family, and society over a five-year period; 3) determination of the most effective and efficient early interventions; and 4) identification of strategies to develop links between agencies serving handicapped children for the purpose of coordinating efforts.

Participants also emphasized the need for sound methodologies, for example, those which include more than one handicapped group; the use of diverse measures of child success; and a focus on causal models and analyses of childhood disability.

A limited number of copies of a monograph summarizing conference presentations and discussion will be available in July 1983. Requests should be directed to the project officer for the conference: Naomi Karp, National Institute of Handicapped Research, Department of Education, Washington, D.C. 20202, (202) 245-0795.

The Micro Conference: A Macro Success

By Donald Barrett, Clearinghouse on the Handicapped

"By 1990, at least 80 percent of all schools will use micro-computers to either assist in the instruction of students, or as administrative/management tools," a speaker boldly predicted at the first national conference on "Use of Micro-Computers in Special Education," sponsored by the Council for Exceptional Children (CEC) in Hartford, CT, March 10-12.

Testimony to the interest in micro-computers, one of today's fastest growing educational tools, was the overflow crowd of 1,500 special education professionals that jammed the Parkview Hilton ballroom. They were not disappointed. The three day conference was packed with lectures, demonstrations, and exhibits designed to familiarize participants with the wonders of the micro-computer.

As one exhibitor put it, "You just can't beat the micro as an instructional aid. It's patient, nonthreatening, friendly, and the kids enjoy it, too."

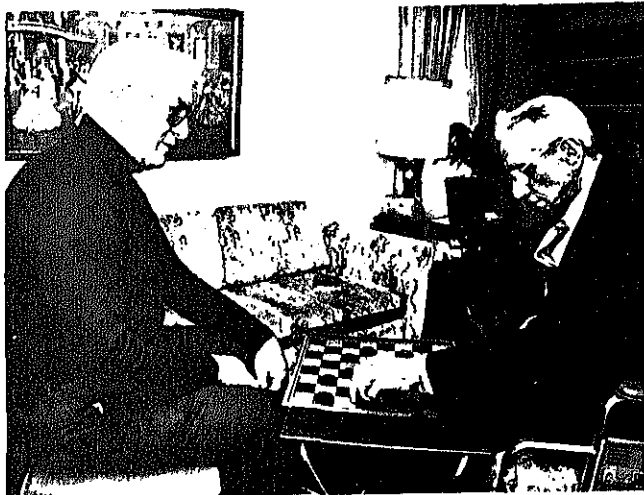
Workshop titles included: The Design of Videodiscs and Micro-Computers in Special Education; Anatomy of a Computer Assisted Instruction Program; Solving Learning Problems with a Computer; and A Soft-Sell for Hardware: the Use of Micro-Computer Technology for Cost-Effective Special Education Management.

One of the striking features of this conference was the real need for information expressed by the attendees. Almost every workshop gave birth to informal information networks. Names and addresses were exchanged, promises of copies of uncopyrighted software were made, and on-the-spot technical assistance was provided.

A school administrator from New York commented, "We get so many requests for our software that we have started hiring some of the handicapped students to duplicate the cassettes."

In response to the ongoing need for quality educational software designed specifically for use with handicapped students, CEC, in collaboration with the Johns Hopkins University, is sponsoring a year-long software competition to stimulate the development of computer programs. Entries should consist of working computer programs, and must be received by the Council by October 15, 1983. Winners and awards will be announced at CEC's 62nd annual convention in Washington, DC, April 23-27, 1984. Entry forms, instructions, and rules for judging are available from: Software Search, Department of Field Services, Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091, (703) 620-3660.

Unique Volunteer Program Aids Stroke Victims



VSRP volunteer James Cassell (left) and aphasic stroke patient Horace Trotta enjoy a friendly challenge on the checkerboard.

Reader response to the article "*Understanding Stroke-Resources and Publications*," which was printed in the November/December Issue of *Programs for the Handicapped* has led to information on a unique volunteer approach to the rehabilitation of aphasic stroke victims.

"I believe that there exists a wide gap in direct one-to-one services for aphasic stroke victims in this country," writes Norma C. Horwitch, director of the Volunteer Stroke Rehabilitation Program (VSRP) which provides this kind of service to stroke victims in New Haven, Connecticut. "While professional health care is customarily provided at the outset of a stroke, and possibly for a time thereafter, such care does not usually address long-term rehabilitation and concomitant psycho-social problems."

VSRP recruits and trains volunteers to visit aphasic stroke victims in their homes. Ms. Horwitch, a former speech therapist, and Dr. William H. Baird, director of the Bridgeport Hospital Stroke Unit and medical consultant to the Easter Seal Goodwill Rehabilitation Centers of New Haven, provide the training and orientation sessions for volunteers.

Whenever possible, volunteers and clients with like interests are matched—readers with readers or movie buffs with movie buffs. The volunteers do not provide speech therapy, although they may work on drills with the clients that are prescribed by the client's speech pathologist. What they provide is a relaxed atmosphere for practice drills, games, or simple conversation and

Families often support the stroke victims but most have difficulty accepting the person as he or she is now, holding tenaciously to memories of the person before the stroke. Since the VSRP volunteers are not acquainted with their clients before the stroke, they have no preconceived notions of what the person should be like. However, during volunteer training emphasis is placed on the adult relationship that is necessary. Even though their clients may be struggling with games designed for a three-year-old, they are still adults and must be treated as such.

"The family is anxious," comments Esther Carroll, a VSRP volunteer. "I'm not. I can wait. Speech flows more easily if the person is relaxed."

Clients of the VSRP program are referred through many channels—doctors and other health professionals, speech therapists, rehabilitation centers, hospital discharge planning coordinators, or friends and family of present clients. To date there are 11 stroke victims being visited by 23 volunteers on a weekly basis. Each client is visited by a rotating team of two to three volunteers for a minimum of two to three visits a week. Each visit ranges from one to two hours.

Dr. Baird points out that while many patients get rehabilitation therapy, insurance only covers it for a limited period of time and then the volunteers become their clients' "lifeline." The service is free to all clients and the program relies on grants to cover a small administrative budget.

In addition to their clients, the VSRP is also interested in offering support to their families. A weekly club meeting is being organized for the client and his or her family members. While the client relaxes with his volunteers in a social atmosphere, the families can also get together for support groups.

Although VSRP is one of only two such programs in the United States, it is modeled after the British Volunteer Stroke Scheme (VSS) which is in its tenth year of operation in England, Canada, and Australia. The British prototype was developed by writer Roald Dahl after his wife, Patricia Neal, suffered three massive strokes in 1965. He recruited community volunteers to help her recover her speech and memory. One of those volunteers, Valerie Eaton Griffith, went on to develop the VSS program which now has over 50 branches in England.

Brochures describing the VSRP program are available with a stamped self-addressed envelope at 10 cents a copy from Greater New Haven VSRP, Inc., 96 Westwood Road, New Haven, CT 06515, (203) 387-3764. Valerie Eaton Griffith's book, *A Stroke in the Family*, is also

Projects With Industry: A Partnership With Promise

The list of large corporations participating in Projects With Industry (PWI) reads like the Fortune 500—IBM, Xerox, Control Data, ITT, TRW, Sears, Lockheed, Boeing, Honeywell and Motorola, to mention a few. They are part of a burgeoning national network of more than 5,000 private corporations, trade associations, labor unions, rehabilitation facilities, and small businesses that are bringing to the field of rehabilitation a whole new set of operating rules based on business technology and marketing techniques. As one PWI official put it, "productivity, cost-effectiveness, accountability, and bottom-line results are now among the new measures of success."

By selecting and training disabled persons for jobs directly related to the manpower needs of business and industry, PWI programs placed more than 36,000 handicapped individuals in jobs by the end of FY 1980. In addition to the incalculable value of gaining competitive employment and economic self-sufficiency, these handicapped workers have returned more than \$78 million in annual earnings for a total federal expenditure of less than \$5.3 million—an excellent investment by any measure.

In an era of spiraling disability costs and scarce federal dollars, this successful partnership between government and private enterprise offers one of the most promising means of not only increasing employment opportunities for disabled people, but also of reversing the trend of ever-increasing disability rolls.

How It Works

Administered by the Department of Education's Rehabilitation Services Administration (RSA), Projects With Industry operates 50 major projects and 50 satellite extensions involving a variety of private sector employers through "voluntary cooperative arrangements." Whether these employers are profit-making or non-profit, each must have the capacity to arrange, coordinate, or conduct training and other employment programs for handicapped individuals in a realistic work setting. Such training and other employment programs must include a planned sequence of training and instruction in occupational and employment skills, and offer reasonable assurance of gainful employment upon successful completion of the programs.

The state vocational rehabilitation agency (or the state agency for the blind) serves as the link between handicapped person and employer. The rehabilitation agencies provide assistance and support by selecting handicapped individuals on the basis of their abilities and potential and providing any special services needed to prepare them for jobs.

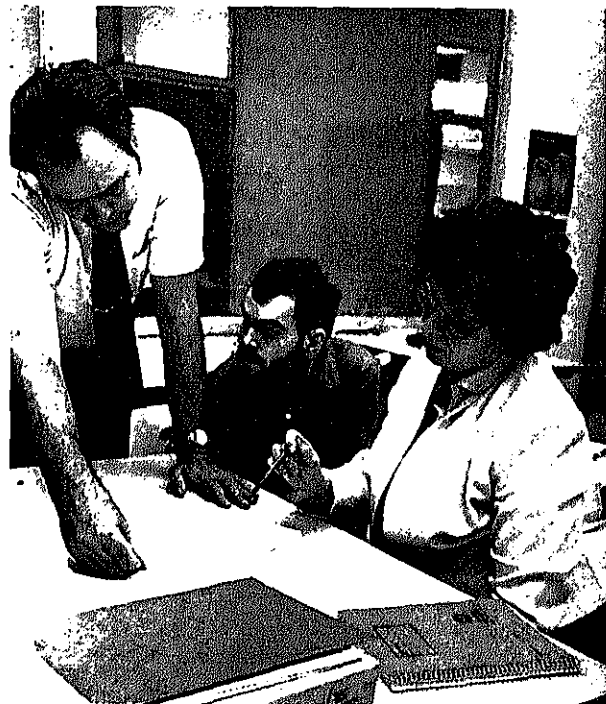
While projects may vary, most fall into one of three ma-

jor models: job placement, work adjustment and skill training. The range of activities provided by the many PWI projects include: on-the-job training; prevocational and other job readiness training; special orientation programs for supervisors, foremen and others; supportive services to help disabled persons retain jobs such as counseling, personal adjustment training, job coaching, etc.; employment of special placement personnel; and trial employment. Other services may also be provided which may contribute to the successful placement and employment of disabled persons.

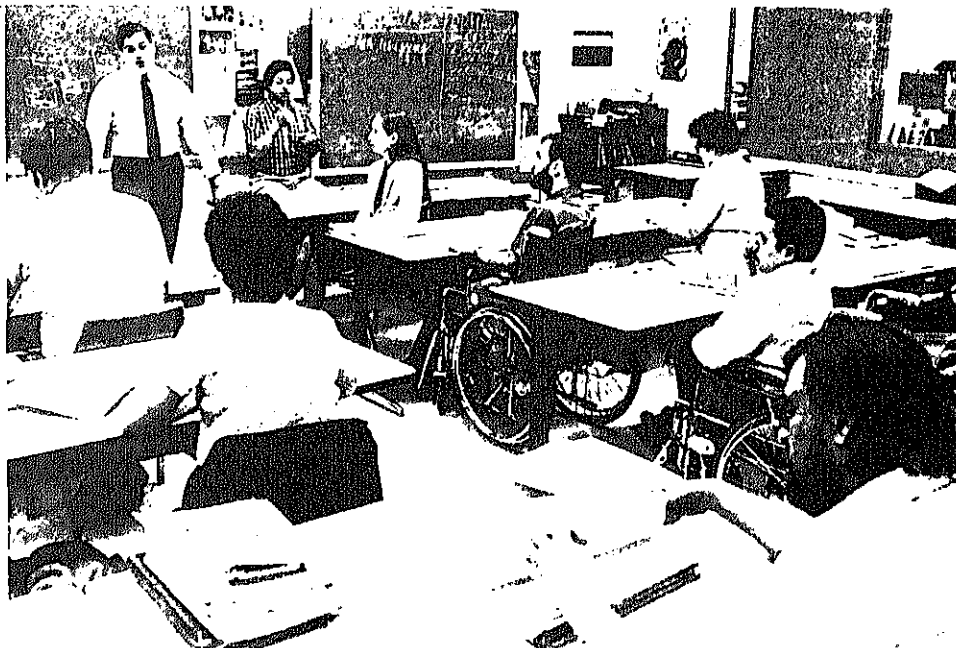
Some Examples of PWIs

Some of the many examples of successful PWI projects illustrating the benefits of the private sector initiative include:

- IBM, one of the pioneer PWI projects, is preparing severely disabled individuals for jobs in the fast-expanding computer technology industry, where demand for trained specialists, whether disabled or not, generally exceeds the supply of available candidates. Through its PWI program, which had placed 425 handicapped persons by the end of FY 1980, four out of five handicapped trainees got well paying jobs. Of the 156 placed in FY 1980, the average beginning salary was \$13,000, with a salary range from \$8,000 to \$20,000.



Individual attention (above) and classroom instruction (upper right) in computer theory and operations are part of an IBM sponsored Projects With Industry program operated at the Long Island, N.Y., Abilities Center.



Photos courtesy of American Rehabilitation

- The Control Data Corporation's PWI program model trains disabled people mainly for clerical jobs, which it reports in the decade of the 1980's will find a shortage of 350,000 jobs per year. Through an active network of state VR agencies, local rehabilitation resources and other PWI projects, the CDC PWI draws recruits from every region of the country.

- With funding assistance from the Department of Labor's CETA program, the Human Services Development Institute of the AFL/CIO and the International Association of Machinists and Aerospace Workers operate projects in several cities in partnership with such major firms as Boeing and Lockheed. These union PWI projects have placed over 2,500 disabled individuals in well paying jobs (\$10,000 to \$18,000), with nearly 600 in 1980 alone at combined earnings of over \$5 million annually.

- The Electronic Industries Foundation's (EIF) program represents one of PWI's most outstanding successes. The Electronic Industries Association, which represents a \$200 billion a year industry, founded EIF and has placed job orders with EIF for thousands of qualified handicapped workers—more than traditional rehabilitation programs are geared at present to provide. Using up-to-date market data and a thorough knowledge of the disabled applicant's capabilities, EIF is nonetheless now placing more than 500 handicapped workers a year in jobs averaging \$10,500, with some as high as \$40,000.

Some large companies, such as Xerox, have assisted the rehabilitation effort by training PWI recommended disabled workers. But, points out William Flynn, vice president for Xerox and former executive vice president of the U.S. Council for IYDP, "as it now stands, we are

What We Have Learned from PWI

There is now convincing evidence that jobs resulting from private management efforts in a partnership arrangement with the rehabilitation community are of better quality in terms of career development and advancement opportunities, as well as the types of jobs made available. They pay more and the employment rate of disabled people is higher—generally a 75 percent rate of success when industry is involved. The retention rate in targeted industries, such as electronics, where severe manpower shortages exist, is also higher than in unskilled areas.

The participation of labor unions in the management of manpower training programs for disabled people also opens up much better job opportunities in skilled and semiskilled areas, paying attractive wages above minimum levels. Labor unions play a significant role in cooperation with major corporations in matching disabled people to good jobs in their industries.

The Projects With Industry program has demonstrated the effectiveness of providing business, industry and labor with a senior responsibility for leadership and direction in training and placement of disabled individuals. In this way, modern business approaches are brought to rehabilitation and the market place is made more sensitive and responsive to the needs of disabled persons. Through this process special training is established to fill jobs already identified in the marketplace, thus assuring a considerably higher rate of placement and retention.

As Frank P. Hadley, an IBM executive on loan to Goodwill Industries of America, puts it, "The PWI program is

By Inez Marie Fitzgerald,
Clearinghouse on the Handicapped

Spurred along by landmark court decisions like the 1978 order to place residents of the Pennhurst State School and Hospital in less restrictive environments, the deinstitutionalization of mentally retarded persons has proven a success, especially placement in community residences with adequate support services. How well mentally retarded people adjust to and function in community settings is well documented¹. But some community facilities were set up quickly, with little opportunity for consideration of a continuum of placement, programs to prepare residents of institutions for the transition, or cost analyses, and information in these areas is still incomplete. Perhaps the area of greatest need is cost analysis.

A number of research projects on costs of various types of residential care have been conducted in the past few years. But comparisons between institutional and community residential care are not easily made. Factors such as higher construction costs in recent years, lower labor costs for community facilities, and differences in direct care and professional services provided are hard to control for in study design. Also, differences between geographic regions, state and local funding patterns, the nature of institutionalized populations, and other variables make it difficult to generalize from study findings.

However, a review of the recent crop of research efforts reveals some findings which appear constant across studies:

- It cannot be said that community residential care is more expensive than institutional care.
- There is a great variation in the cost of operating community facilities, even within geographic areas.
- The development of community residential facilities entails a shift of public funds, with fewer federal monies used and a greater dependence on state and local funding.
- Community settings help mentally retarded people attain a higher level of functioning and increased independence.

The overwhelming conclusion seems to be that additional cost studies are necessary. These studies should use random sampling techniques and include a large geographic area, the entire nation if possible, and should control for as many variables as possible. But in the meantime, existing studies can still prove very use-

ful to human service planners and administrators.

The summaries that follow include reports and papers falling into several different areas: a national study, a major longitudinal project, state sponsored studies, a few independent studies which have been published, and a report compiling various research findings. As understanding of cost is dependent on a knowledge of funding patterns, this is where we begin.

Federal and State Funding Patterns

An unpublished report prepared in 1981 by the Department of Health and Human Services, Office of Service Delivery Assessment, Region II, analyzes federal and state expenditures in the area of mental retardation. To acquire data on the roles of federal, state, and local government and the private sector, research teams visited 16 states and conducted telephone interviews with officials in the other 34 states.

The study reports that public spending for residential and support services for mentally retarded persons was an estimated \$11.7 billion per year, of which the federal portion was \$5.4 billion and the state share \$6.3 billion. Only 16 percent of state expenditures were used to match federal funds. Half (\$5.9 billion) of public funds were spent on residential care, including \$3.7 billion for care in institutions, \$.7 billion for community residences, and \$1.1 billion for care in other long-term facilities such as nursing homes and mental health institutions. The estimate for community base support services was at least \$4.5 billion. In addition, about \$1.3 billion went to SSI/SSDI payments made to individuals in independent living situations, and from states to counties which provide residential care and services.

It is difficult to estimate private contributions of voluntary organizations and parents. The report quotes a figure of \$200 million, about 6 percent of the cost of residential care. However, experiences of researchers indicate that this is a low estimate.

State mental retardation agencies contacted by the research teams indicated that 67 percent of their budgets was spent on residential care, at both the institutional and community level, with most funds going to institutions. The average per diem rate was found to be \$80 for state institutions, with rates for individual states ranging from \$46 to \$283. The report cites several factors influencing the rates: per diem rates for institutions in the northeast are 20 percent higher than in the rest of the country; capital expenditures of \$1 billion nationally to upgrade institutions have been factored into per diem rates; and the level of disability of residents influences composition of a facility's staff, which accounts for 75 percent of institutional costs.

¹ See, for example, *Coming Back, The Community Experience of Deinstitutionalized Mentally Retarded People*, by Elinor Golley et al., 1978, available for \$19.50 from Abt Associates, 55 Wheeler Street, Cambridge, MA 02138, (617) 492-7100.

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date care facilities for the mentally retarded (ICF's/MR), whether in the community or state institutions, were higher than for non-ICF/MR settings. The per diem in institutional ICF's/MR averaged \$80, while the community ICF/MR per diem averaged \$65. The cost of non-ICF/MR group homes was significantly less, averaging \$50 a day, including support services. Such group homes were financed with client SSI/SSDI payments, state funds, HUD section 202 loans and section 8 rent supplements, food stamps, parent/resident fees, and donations.

The report points out that while it is less expensive to provide residential care by using these multiple funding sources, it is easier to use the ICF/MR program, which has one set of regulations and reporting requirements.

A Note on Medicaid Funding

One of the most crucial issues in the establishment of community based programs is the use of Medicaid funds, which have always been plentiful for states providing institutional care to mentally retarded persons. In 1972, Congress extended Medicaid coverage to include ICF's/MR. "Active treatment" (medical or rehabilitative) and 24-hour supervision are required for ICF/MR certification for Medicaid funding. Originally, this program was intended to upgrade services available in large facilities. However, 1,000 to 1,200 small ICF's/MR (serving 15 or fewer clients) are now operating, a number of these in Minnesota and New York.

The Health Care Financing Administration, which oversees the Medicaid program, is currently in the process of developing new proposed standards for ICF's/MR. Publication of the proposed standards in the *Federal Register* will take place in the fall of 1983 at the earliest. Persons interested in expressing concerns or asking questions about the standards may contact Dr. Wayne Smith, Health Care Financing Administration, First Floor Dogwood East, 1849 Gwynn Oak Avenue, Baltimore, MD 21207, (301) 597-5913.

Major National Study

The Center for Residential and Community Services in the Department of Psychoeducational Studies at the University of Minnesota, formerly the Developmental Disabilities Project on Residential Services and Community Adjustment, has been a primary source of data on residential service for developmentally disabled people in recent years. In a 1980 study published by the Center, cost data were collected from a national sample of 75 public residential facilities and 161 community residential facilities. From these data a profile of national patterns of revenues was delineated. Cost analysis was performed on a number of variables to identify relationships among them.

In designing the sample of public institutions to be surveyed, the researchers chose facilities representing six size categories and four geographic regions (northeast, north central, south, and west). Four thousand commu-

nities were sampled according to size class and geographic region. (Because of nonresponse on the part of several larger community facilities, this size category is underrepresented in the sample.)

Through a survey administered in 1978, data were collected on revenues, expenses, and capital investments of the facilities. The report estimates total revenue of public institutions in 1977-78 at more than \$2.6 billion, 98 percent of which is received from the government, 2 percent from the resident or family, and less than 1 percent from donations. Community residences received about \$484 million, of which 72 percent came from the government, 19 percent from the resident or family, and 9 percent from donations. It is interesting to note that for public residences, a much greater proportion of funding was received from the state (nearly \$2 billion), while only roughly \$120 million in state monies went to community facilities. For community facilities, regional, county, and other (not identified) government funding increased (no regional funds were involved in public institutions), as well as resident and family contributions, and donations.

Average (mean) per diem costs were \$52.57 in institutions, and \$20.29 in community residences. (Per diem charges were \$49.91 and \$18.71 respectively.) The report gives numerous analyses based on variables associated with geographic location, staff-resident ratio, staffing patterns, proportion of severely and profoundly mentally retarded residents served, and others.

The publication also contains an extensive review of the literature, a historical analysis of deinstitutionalization, and an evaluation of deinstitutionalization as a public policy.

Copies of *The Cost of Public and Community Residential Care for Mentally Retarded People in the United States* are available for \$5 from the Center for Residential and Community Services, 207 Pattee Hall, University of Minnesota, 150 Pillsbury Drive SE, Minneapolis, MN 55455, (612) 376-5283.

Another of the Center's publications, *Sourcebook on Long-Term Care for Developmentally Disabled People* by Charlie Lakin et al., gives a summary of recent research on residential care. In addition to cost, several other areas are covered: trends in residential care, client characteristics, availability of services in public institutions and private facilities, and patterns of discharges and admissions.

The section on cost contains an excellent review of the current knowledge in this area, including good data on the rising cost of institutional care. In looking at the factors associated with this increase, which has slowed since 1978, the authors have singled out services of direct care staff and professionals providing medical, psychological, and other therapeutic care. With both direct care and professional services, there has been a significant decrease in the ratio of residents to staff. For example, in fiscal year 1965 there were 4.4 residents per direct care worker. In fiscal year 1981 the

ratio had decreased to .78 residents for each direct care employee. Each professional support person served an average of 33 residents in 1965, and 5.25 persons in 1981.

Another variable affecting costs is the ability of the residents to care for themselves. The significant change in the proportion of profoundly retarded people in institutions, from 27 percent in 1965 to 55 percent in 1981, has led to a greater need for personal care services.

Lakin and his colleagues point out the difficulties entailed in making comparisons between institutional and community facilities. One is the lack of detailed cost data on community based care. Also, factors such as the types of residents in each setting, geographic location, state reimbursement regulations, the types of programming included in the per diem, and other variables have an effect on the per diem.

Copies of the *Sourcebook on Long-Term Care for Developmentally Disabled People* may be ordered for \$4 from the Center for Residential and Community Services, address above.

Longitudinal Deinstitutionalization Study

In a five year study supported by the Office of Human Development Services, Department of Health and Human Services, Temple University and the Human Services Research Institute began in 1979 to analyze the impact of U.S. court orders to place residents of Pennsylvania's Pennhurst State School and Hospital in less restrictive community residences. Researchers are examining how clients fare both before and after deinstitutionalization and what the interrelationships are among the primary actors in the deinstitutionalization process: policy makers, government agencies, service providers, legislators, courts, and parent organizations. A detailed journal is being used to record how these groups interact to effect policy change.

A cost analysis, an important part of the project, compares the difference between institutional and community based care. In this study 70 former Pennhurst residents living in community facilities were paired with 70 Pennhurst residents. The clients were matched by a number of variables: age, IQ, sex, level of retardation, number of years institutionalized, and self-sufficiency. The costs of all services received by the clients (residential, case management, medical and day programming costs, and public assistance) were determined. Comparisons between the two groups revealed that the community programs are more cost effective, although the cost per client varied considerably (\$22,590 to \$104,565). This variation can be largely attributed to the cost of the residence (\$13,034 to \$90,651) and day programming (\$1,451 to \$17,143). The mean cost was \$40,284; the median was \$36,035. It should be noted that three clients at community residences had very high costs (all over \$75,000). The mean cost of care at

based care are a low level of adaptive behavior, age, and the number of developmental programs (self-care training, therapy). The number of day programming hours was negatively associated with cost, an interesting relationship.

Temple University researchers found that the community programs offered more services and tended to promote greater client independence. In an article published in the *American Journal of Mental Deficiency* (Vol. 86, No. 6, 1982, pp. 581-587), "A Matched Comparison of the Developmental Growth of Institutionalized and Deinstitutionalized Mentally Retarded Clients," James Conroy and colleagues report on measurements of the adaptive behavior change in the Pennhurst and the deinstitutionalized clients, and found that only the latter group showed any significant growth. While community placement resulted in lower costs for care of clients and lower federal costs, state and local costs are higher.

This study was limited to clients in one institution and in community residences within a small geographic area. Another factor limiting application of study results is the fact that the clients and programs were under the supervision of the court which ordered the deinstitutionalization. Thus the researchers stress that their conclusions point out directions for future research rather than generalizations relevant to all institutional and community facilities. However, their results clearly indicate that for the clients in the study, deinstitutionalization offered more services and improved adaptive behavior at a lower cost.

State Studies

Studies by various states have documented the superiority of community based residential services and the need for an increase in those services.

Minnesota

An unpublished 1979 report on a residential care study conducted by the State of Minnesota analyzes a number of policy options for residential care of mentally retarded and mentally ill persons, and those dependent on chemical substances. Based on criteria related to the most effective use of resources, the most effective treatment in the least restrictive setting, and cost containment at the state and county level, the study recommended placing fully mobile severely and profoundly retarded residents of state hospitals in community based programs whenever possible. The per diem rate in 1978 was \$53.65 for state institutions and \$30.67 for community residences (for those licensed in 1976-78; residences opening earlier had a slightly lower rate), adjusted to \$46.25 to include \$15.58 for outside services.

Eliminating from the community residences a population not serviced by state institutions (moderately to borderline retarded with no behavior problems) results in a per diem of \$49.85 percent less than the state in-

able to examine the fiscal and programmatic effectiveness of community residences for severely and profoundly developmentally disabled persons in the New York City area. A large number of residences were established in the State as a result of the Willowbrook Consent Decree, which required that the number of inpatients at Willowbrook (now called the Staten Island Developmental Center) be reduced from 2,761 in 1975 to 250 in 1981, and that Willowbrook class members (plaintiffs in a 1975 class action suit) be placed in the least restrictive residential environment appropriate to their needs. Working within a tight timeframe, the State became involved in the establishment and operation of community residential programs. Voluntary agencies also operate a number of residences. As a result of these efforts, about 3,000 people with severe and profound mental retardation resided in community settings in 1982.

The Commission on Quality of Care for the Mentally Disabled undertook a review of 24 community residential facilities, nine of which were operated by the State and 15 by five different voluntary agencies. The average cost of institutional care per resident was \$37,024 in FY 1979-80. (This figure excludes \$12,000 for day programming.)

The average cost for community residential facilities was \$28,639 (also excluding day programming costs).

It is important to note that the annual per client cost of residences operated by voluntary agencies was significantly lower than the cost of state institutions, while the cost for state operated community residences (\$37,055) was nearly the same as the state institutional cost. This difference can be explained by the fact that the state residences serve clients who are more disabled. However, the high cost of apartments operated by the State cannot be solely explained by the more severe disabilities of clients served; the apartments cost \$39,156 per client per year, more than the cost of institutional residential care. Since state-run apartment residences cost more and offer no advantages, the Commission recommended their discontinuance.

The Commission also found that residences serving clients of similar disability levels had widely ranging staff-to-client ratios and costs, and some residences serving less disabled clients had higher costs than comparable residences serving more disabled clients. These variations in the level of staffing and costs were not readily explainable based on any apparent treatment or programmatic consideration.

Regarding the quality of care provided by community based residences, the study concluded that they offer many advantages to clients, such as increased mainstreaming in society, personalized care, training, therapy, and recreation. It was found that the residences operated by voluntary agencies were superior to the programs run by the State. For example, the voluntary programs provided more types of services (more nursing, medical and dental services); updated treat-

ment plans and performed client assessments more regularly; and addressed more of the identified needs of clients. (State operated residences in upstate New York were not included in this study.)

The Commission after reviewing study results recommended that the State pursue its policy of implementing community residential programs for people with severe and profound mental retardation, correcting the factors that led to a poorer standard of performance than that of the residences operated by voluntary agencies.

Nebraska

A study performed by Touche Ross and Company, Kansas City, Missouri, for the Nebraska Departments of Public Institutions and Public Welfare examined differences in the provision of a full range of services to clients in community based and institutional residential programs. In addition to costs for residential care, costs were accumulated for day training, support (therapy, recreation), social services, medical care, and administrative overhead. Costs for services not provided by the facilities, such as Medicaid, income maintenance, school district educational programs, and generic services, were also included.

The annual cost in fiscal year 1979 to support a client receiving a full range of services was computed for community facilities in each of the six regions of Nebraska and for the state residential facility. The cost per client for institutional care was \$19,500; costs for care in community facilities in the six regions varied considerably, from a low of \$9,400 to a high of \$19,700, but were on the average lower than the cost of serving a client in the state institution. For four regions the cost per resident was under \$15,000.

The primary reason for cost variations among regions was found to be the number of hours of direct care services provided. The high cost of institutional care was attributed to several factors: 1) high overhead costs, which remain relatively unaffected by decreases in client population; 2) participation of clients in community based facilities in home maintenance activities (cooking, cleaning, etc.); 3) the higher level of skills and fewer support needs of clients served in community residences; and 4) the greater flexibility community residences have in placing clients (they can serve lower need clients in less costly programs, and integrate high need clients into facilities serving predominantly moderate need persons without increasing staff).

Independent Studies

In a study which was conducted on a smaller scale than those discussed above, the Teaching Research Division of the Oregon State System of Higher Education compared costs of caring for developmentally disabled children in small group homes as an interim placement with the cost of institutional care. Dave Templeman et al., in an article entitled "Cost Effectiveness of the Group Home," (*TASH Journal*, Vol. 6, Winter 1982, pp. 11-16) found that while the cost per child per month

moving into foster homes (62 percent) or their natural homes (33 percent). Only five percent were returned to institutions; 86 percent had lived in an institutional setting before their group home experience. The authors estimate that the use of group homes for transitional placement results in a 57 percent savings per child in state payments for institutional costs.

An article entitled "Evaluation of Residential Alternatives" by Laird W. Heal and Thomas J. Laidlaw offers a framework for evaluating various types of placements. Their analysis is built on six different groups of variables: approximation to normalization, levels of competence, client satisfaction, satisfaction of others (neighbors, supervisors, family, etc.), residential classification (type and "climate" of residence) and cost of services. In the cost of services section the authors give a good review of cost analyses performed in the 1970's, citing figures obtained in cost comparison studies. They advocate uniform cost accounting in human services in general, and community residential care in particular, so that comparative cost analyses can be conducted.

Several problem areas in determining the cost of residential services are outlined in the article: 1) it is difficult to separate capital costs from operating costs; 2) costs of resident care are not easily distinguished from those of other services; 3) the true value of volunteer time and gifts is not always ascertained; and 4) residents' contributions to their own care and maintenance of the facility are not always taken into account.

The article appears in *Integration of Developmentally Disabled Individuals into the Community*, a compilation of papers on topics related to deinstitutionalization edited by Angela R. Novak and Laird W. Heal. Other topics covered are: factors affecting success of community placement, generic services for developmentally disabled people, physical and social integration, and relevant legislation and litigation. The book may be ordered for \$12.95 from Paul H. Brookes, Publishers, P.O. Box 10624, Baltimore, MD 21204.

James C. Intagliata et al. in an article entitled "Cost Comparison of Institutional and Community Based Alternatives for Mentally Retarded Persons" (*Mental Retardation*, Vol. 17, June 1979, pp. 154-156) present data from a cost comparison study which received funding from the Administration on Developmental Disabilities. As in other studies, the researchers found that group homes were less expensive (\$9,255-11,000 per resident year) than the institution considered (\$14,630), with variations depending on the level of disability of the residents. (Costs for professional services are not included.) However, the other community alternatives, family care homes and the home of the natural family, were significantly less (\$3,130 and \$2,108 respectively).

tion at Texas Tech University has produced a summary document on cost comparisons, *Comparative Costs of Public Residential and Community Residential Facilities*, by Gerard J. Bensberg and Janet J. Smith. This paper summarizes data from various surveys, not all of which have been published, and discusses some of the factors accounting for cost differences. The report, which was published in January 1983, may be ordered for \$2 from the Research and Training Center in Mental Retardation, Texas Tech University, P.O. Box 4510, Lubbock, TX 79409, (806) 742-3131.

'Baby Doe'

(Continued from page 2)

tions also set up a "Hot Line" at HHS to receive reports of violations of the regulations.

The American Academy of Pediatrics took HHS to court, however, and on April 14 Judge Gesell invalidated the regulations, declaring them "arbitrary and capricious and promulgated in violation of the Administrative Procedure Act."

But HHS points out that, although the Court decided it was not appropriate in that case "to consider the ramifications and scope of Section 504" as it relates to health care for handicapped infants, the opinion noted: "Given the language of the statute and its similarity to other civil rights statutes which have been broadly read, it cannot be said that Section 504 does not authorize some regulation of the provision of some types of medical care to handicapped newborns."

"We are encouraged that Judge Gesell's ruling acknowledges that, at least in certain instances, Section 504 of the Rehabilitation Act of 1973 authorizes the government to protect handicapped newborns from the discriminatory denial of medical care," Heckler said.

Some have speculated that this leaves open the possibility that the regulations may be rewritten to conform to the Court's objections.

Dialysis Payments and Medicare

Like most other medical costs, the cost of the kidney dialysis program for the 63,500 Americans whose lives depend on it has soared into the financial stratosphere," Secretary of Health and Human Services Margaret M. Heckler said on March 25, 1983, as she signed final regulations "which will insure continued dialysis treatment for all Americans who depend on the treatment and Medicare's coverage, while reining in the runaway costs."

Medicare will henceforth set its dialysis payment rates in advance for both hospital and freestanding dialysis facilities. There will be separate rates for hospitals and independent facilities, as mandated by Congress. As expensive home dialysis will be encouraged in areas where it is medically appropriate.

Heckler is convinced that these rates will be sufficient to maintain available services. Since these new rates were first proposed in November 1981, 114 new facilities have been opened," said Mrs. Heckler.

Under the new system, hospital dialysis facilities will be paid an average of \$131 per treatment while independent facilities will receive an average of \$127. The rates will vary slightly, region-by-region to reflect local costs. Facilities which provide dialysis services at less than the prospectively set rate will keep the difference.

The new regulation encourages home dialysis on two conditions: (1) the same rate will be paid for less costly home dialysis as for in-facility treatment; and (2) a monthly per-patient payment for physician services will be made to both home and in-facility dialysis.

The regulation promulgated by HHS was mandated by Congress which required us both to develop a prospective rate system and to encourage home dialysis whenever it is medically appropriate," Secretary Heckler said. "While home dialysis is not an appropriate treatment for everyone, we should and will encourage it as a convenient, efficient alternative when it fits the needs of an individual patient."

Home dialysis typically costs \$97 per treatment. "Our studies show that 30 to 40 percent of dialysis patients could use home dialysis, although only about 17 percent do so today," Secretary Heckler said. "The new regulation takes some other forward steps," she continued, and cited:

• New short-term approval for facilities needed for emergency purposes, for example, in case of strike or bankruptcy at an existing facility.

• Exceptions in the new rates for facilities that have unusually high costs, especially sole providers in isolated areas, and for protecting patients who rely on sole providers. Ex-

ceptions will also be allowed for self-dialysis training costs.

- A two-year phase-in period that establishes a "floor" on the wage differential so that hospital facilities will be paid at least \$122 and independent facilities at least \$118. This protects rural facilities from possible adverse effects of immediate implementation of the new payment method.

The new regulations have gone to the Office of Management and Budget for review prior to publication in the *Federal Register*.

National Council Issues Annual Report

The National Council on the Handicapped has published its 1983 Annual Report which chronicles the activities of the Council and offers an overview of Federal agency activities for handicapped persons, as well as the status of research on problems pertaining to handicapped people in the U.S.

Recommendations and future plans of the Council include:

- Review and evaluate the effectiveness of special and vocational education programs and state vocational rehabilitation programs with emphasis on coordination of these initiatives to assure a continuum of service to the disabled adolescents as they move from the purview of special education to vocational rehabilitation;
- Develop a program of action to increase the effectiveness of state vocational rehabilitation programs through improved interface with the private sector;
- Establish Model National Centers on Employment of the Disabled. In addition, develop a program to identify and respond to manpower requirements of the future—especially those utilizing computers, robotics and other high technology;
- Promote programs of disability prevention by better health education and by illness and accident prevention;
- Assess means for the review and evaluation of the effectiveness of all other federal policies, programs, and activities concerning disabled and handicapped individuals;
- Strengthen the disability benefits of the Social Security system.

Copies of the report are available without charge from: National Council on the Handicapped, Room 3116 Switzer Building, 330 C Street, S.W., Washington, D.C. 20202.

Announcements

ABLEDATA Now Available

The ABLEDATA database on commercially marketed equipment and aids is now available online to the public through Bibliographic Retrieval Services (BRS). This file, an important part of the ABLEDATA system, located at the National Rehabilitation Information Center (NARIC), contains over 6,000 entries on products covering all categories of rehabilitation needs: personal care, home management, vocational training, education, mobility, seating, transportation, communication, recreation, and ambulation.

BRS users have instant access to an array of databases via their own computer terminals. Those interested in subscribing to this service may contact BRS, 1200 Route 7, Latham, NY 12110, (800) 833-4707 outside New York; (518) 783-1161 in New York State.

NARIC has scheduled a series of workshops to train professionals to search the ABLEDATA file. Sessions are scheduled for June, August, and October 1983. Workshop registration, including training materials, is \$200 per person.

The ABLEDATA system continues to be available through a network of trained information brokers, who, in addition to performing searches of the database, refer requestors to local and regional resources and supplier information. Those in areas not served by brokers receive service from the ABLEDATA headquarters office at NARIC.

Additional information on ABLEDATA is available from Marlan Hall, ABLEDATA System Manager, NARIC, 4407 Eighth Street, N.E., Washington, DC 20017, (202) 635-6090.

Spinal Cord Injury Conference Announced

The National Spinal Cord Injury Association has announced its annual convention to be held July 31-August 4, 1983, at the Americana Congress Hotel in Chicago, Illinois. Leading authorities on spinal cord injury will give major presentations and discuss such topics as spinal regeneration and implantation, engineering and computers, accessibility, legal issues, independent living, sexuality, and other aspects of care and cure. People with spinal cord injuries, professionals, families, and friends are expected to join together to learn, share, socialize and plan programs. For further information contact: Illinois Chapter, National Spinal Cord Injury Association, P.O. Box 468, Palos

The Federal Register and The Federal Funding Process

An article was published in the March/April issue of *Programs for the Handicapped* titled "The Who, What, When and How of the Federal Funding Process." Information on how to search the *Federal Register* appeared on page 9. Since that article was printed, a list of libraries where the *Federal Register* and the *Code of Federal Regulations* are available for examination free of charge appeared in the April 20, 1983 *Federal Register*. A xerox copy of the library list is available from the Clearinghouse on the Handicapped, Room 3119 Switzer Building, 330 C Street, S.W., Washington, D.C. 20202.

The Office of the Federal Register's list will be updated annually unless public interest requires more frequent publication. Any library that maintains these publications, makes them available to the public, and wishes to be included on future lists should write to the Director of the Federal Register, National Archives and Records Service, GSA, Washington, DC 20408, or phone (202) 523-5227 giving the name and address of the library.

NCRE Receives NARIC Award

The National Council on Rehabilitation Education (NCRE) has received a Special Citation for outstanding participation in a "Rehabilitation Research Review" project. The award was presented by Dr. Douglas Fenderson, Director of the National Institute of Handicapped Research (NIHR) on behalf of the National Rehabilitation Information Center (NARIC) which initiated the project in response to its 1983 NIHR contract.

The project will create 20 state-of-the-art analytical summaries and annotated bibliographies on topics ranging from "The Family Role with Disabled Persons" to "Measuring Vocational Rehabilitation Success." To assure quality research and maximum participation of professionals in the field of rehabilitation, NARIC invited NCRE to serve as co-sponsor for the project.

In presenting the award, Dr. Fenderson commented that he has no doubt that "the outcome of this co-sponsored endeavor will be a series of conclusions, recommendations and observations of great use to NIHR." Availability of the summaries will be announced as they are published.

Dr. Kenneth W. Reagles of Syracuse University was commended for his leadership as Chairperson of the Rehabilitation Research Review Advisory Committee. The citation was presented at the NCRE meeting in

Announcements

AMI Conference Planned

The Alliance for the Mentally Ill has announced its 5th National Conference to be held at Washington University, St. Louis, Missouri, on August 4-7, 1983. The theme for the 1983 conference is "Coping with Mental Illness in the 80's: Progress through Research/Rehabilitation." The National Alliance for the Mentally Ill (NAMI) is a coalition of nonprofit, self-help, and advocacy organizations dedicated to improving conditions for the mentally ill. Speakers include Agnes Hatfield, Ph.D., President of NAMI; a number of distinguished professors of psychiatry, who will speak on Schizophrenia, the Epigenetic Puzzle; Affective Disorders; Rehabilitation and the Mentally Ill; and Family Coping, How It Can Be Improved. Other speakers will cover Training in Community Living, Deinstitutionalization, a Legal Issues Overview, and Psychopolitics: The Role of AMI. Workshops are planned covering such subjects as diagnosis, community living, legal planning, and advocacy efforts. The informal setting of the Washington University dormitories and other facilities will provide an economical opportunity for participants to meet and exchange ideas and information. Contact: The National Alliance for the Mentally Ill, 1234 Massachusetts Avenue, N.W., Washington, DC 20005, (202) 783-6393.

Talent Search In Arts Announced

Arts Recognition and Talent Search (ARTS) is a national program that identifies, recognizes, and encourages high school seniors, or other 17- and 18-year-olds, who have demonstrated excellence in dance, music, theater, visual arts, or writing. The registration deadline for the 1983-84 talent search is October 3, 1983.

ARTS is a program of the National Foundation for Advancement in the Arts, which provides individual cash awards of up to \$4,000. Opportunities for scholarships and internships are made available through the ARTS Scholarship List Service. Disabled Americans are among the groups targeted by the ARTS Affirmative Action Program for outreach services, which ensures universal access for under-represented groups in the arts and works to guarantee that all who are eligible have an equal opportunity to participate.

A folder describing the entry qualifications for each skill, a poster encouraging the young people to apply,

Canine Companions

Canine Companions for Independence is a nonprofit organization in Santa Rosa, California, which provides specially selected and trained dogs to enable people with disabilities to lead more personally fulfilling lives. With the aid the dogs provide, the need for human attendant care is reduced. Provided with this means of gaining independence, participants are encouraged to expand their horizons, such as going to college, getting jobs, and beginning to live in the mainstream of society.

CCI was started in 1975 by Bonita Bergin, who is the current director. She became aware of the potential for using dogs to help disabled people become more independent during her studies in the master's program in special education. The project has developed into an internationally known organization with a training center, a paid staff, and contacts throughout the United States and Europe.

Canine Companions provides three types of trained dogs:

- **Service Dogs**—Assist the orthopedically disabled by performing physical tasks that increase the individual's mobility and independent life style. Tasks performed vary from individual to individual, but include such tasks as turning lights on and off, opening doors, carrying a pack, fetching dropped items, or pulling wheelchairs up ramps and curbs.
- **Signal Dogs**—Work to alert the deaf and hearing impaired to sounds in their environment such as doorbells, alarm clocks, telephone/TTY, smoke alarms, and baby cries.
- **Social Dogs**—Provide that needed love and interaction called "pet therapy" in hospital and school environments. These dogs successfully reach and communicate with individuals that technology and trained personnel cannot.

CCI has been totally supported by donations and grants since its beginning in 1975. In 1982 the District 4C-7 Lions Club set up a foundation to ensure on-going support for CCI. Further information about the program or on applying for a dog companion is available from: Canine Companions for Independence, P.O. Box 446, Santa Rosa, CA 95402, (707) 528-0830.

NEW PUBLICATIONS

ADULT EDUCATION

Adult Education for the Handicapped by Gordon Larson of Rutgers University examines the challenges associated with education for the physically handicapped, the blind, the deaf, and the mentally retarded adult population in the United States. In this book, Larson reviews studies of adult education programs that have dealt successfully with related problems, giving particular focus to accessibility, specially designed instruction, and cooperative planning for programs. It includes guidelines for education programs for handicapped adults, and lists resources and references for more in-depth planning and program implementation. *Adult Education for the Handicapped*, 37 pages, is available at \$4.25 from: National Center for Research in Vocational Education, The Ohio State University, 1960 Kenny Road, Columbus, OH 43210; (614) 486-3655 or toll-free outside Ohio, (800) 848-4815.

REHABILITATION

Report from the Study Group on Rehabilitation of Clients with Specific Learning Disabilities is intended to provide basic information and guidelines to state agencies for implementing meaningful services to clients with Specific Learning Disabilities (SLD). Although some states have had programs for this population for several years, and the benefits of their experience are discussed in this manual, in most states these clients were served on the basis of other physical or mental disabilities rather than SLD as the major handicapping condition. Until 1980 SLD was not recognized as a rehabilitation problem or a handicap to vocational adjustment. Advocacy groups have brought the problems and needs of SLD individuals to the attention of the public and local, state and federal governments. As a result, specific charges have been issued to education, rehabilitation and other agencies that SLD individuals must be served more effectively. This document, developed by the Ninth Institute on Rehabilitation Issues under a research and training center grant from the National Institute of Handicapped Research, contains the following chapters: A Historical and Philosophical Review of SLD; Description of the SLD Population; Administrative Issues; Case Process; and a chapter on Utilization of the Document by Rehabilitation Trainers. This 91 page softcover book is available at \$4.50 a copy (Item #1188) with checks payable to the Arkansas Rehabilitation Research and Training Center, from: Publications Department, ARR&TC, P.O. Box 1358, Hot Springs, AR 71901.

LIBRARIES

In *The Mainstreamed Library: Issues, Ideas, Innovations*, Barbara H. Baskin and Karen H. Harris have selected and commissioned articles that consider the issues libraries must confront to meet the challenges posed by mainstreaming. The book is intended as a guide for school, public, academic, institutional, and special librarians seeking to develop a full range of services for patrons with special needs. The articles provide a basis for the procedures, techniques, and selection of materials recommended for use with exceptional patrons. They also provide detailed descriptions of programs which can be readily adapted to the needs of individual libraries. The collection includes various papers on each of the following topics: The Physical Environment, Materials Section, Technology, Software, Program, and Outreach, with an introduction to each section. This 294 page hardcover book is available at \$35 from: Order Department, American Library Association, 50 East Huron Street, Chicago, IL 60611.

CLOTHING

Dressing with Pride by Evelyn S. Kennedy is intended to meet special needs that are not presently met by clothing manufacturers. Ms. Kennedy is the Executive Director of PRIDE Foundation (Promote Real Independence for the Disabled and Elderly). The instructions for changing clothing to accommodate special needs are written specifically for the person who has limited knowledge of home sewing skills. They show the inexperienced how they can easily modify and alter regular clothing. This first volume of the book covers the selection and application of convenience fasteners for greater ease in dressing and undressing. It covers alterations of twelve of the most commonly used articles of clothing—five children's garments and seven for adults, ranging from underwear to shirts and dresses. This 116 page spirally bound book is available at \$11 from: P.R.I.D.E. Foundation, 1159 Poquonnock Road, Groton, CT 06340, (203) 447-7433.

NEW PUBLICATIONS

TRANSPORTATION

The Volunteer Transportation Program: Some Suggestions and Cautions in the Use of Volunteers as Drivers, Escorts and Other Transportation Workers was originally sponsored by the Tennessee Department of Transportation and has been reproduced for sharing with a national audience. It is designed to aid social service agencies, charitable organizations, and churches in using volunteers to provide transportation for the elderly, handicapped, or needy persons. It offers suggestions on organizing volunteer transportation programs and avoiding common problems and pitfalls. A resource section and a "Volunteer-Driver Guide" are included. This 75 page softcover book is available at \$5 (Stock No. 050-000-00459-7) from: Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402.

MUSIC THERAPY

Guide to the Selection of Musical Instruments with Respect to Physical Ability and Disability is a new book for health professionals and music instructors who are interested in using music as a therapeutic tool. It was developed by Moss Rehabilitation Hospital and Settlement Music School in Philadelphia, as an outgrowth of their cooperative Therapeutic Music Program. The Program, started in 1976, uses the playing of musical instruments to strengthen affected limbs in handicapped children. It also encourages music instruction as a means of socialization and mainstreaming.

The Guide was developed with support from the Bureau of Education for the Handicapped (now Special Education Programs, Department of Education). Barbara Elliott, a registered occupational therapist, was principal researcher and author. The Guide is organized according to instrumental families: strings, brass, percussion, woodwinds, and keyboard. Each section provides basic information on the instruments and how they produce sound, details the functional ability necessary to play, and illustrates playing positions.

This 20-page illustrated book is available at \$7.75 from: Magnamusic-Baton, 10370 Page Industrial Blvd., St. Louis, MO 63132. For further information about the Therapeutic Music Program, contact: Settlement Music School, 416 Queen Street, Philadelphia, PA 19147.

PERSONAL ASSISTANCE

Handling the Handicapped: A guide to the lifting and movement of disabled people has been published by the Chartered Society of Physiotherapy for the second time. The book was published primarily to show the correct manner in which handicapped people should be lifted or moved, and is intended for relatives, friends, physiotherapists, nurses or members of voluntary organizations who live or work with handicapped people. The information is meant to benefit both the person who might injure himself by using improper lifting techniques and the disabled person who benefits from skillful handling. The softcover edition is available at \$7.95 plus \$1.30 postage and handling from: Springer Publishing Company, Inc., 200 Park Avenue South, New York, NY 10003, (212) 475-2494.

INFORMATION RESOURCES

The Arthritis Information Clearinghouse has prepared a directory of 67 private and government organizations that provide information on arthritis through publications and special services. The *Directory of Information Resources* is intended as a reference guide for physicians, nurses, therapists, educators, and librarians. The sources listed include associations, foundations, clearinghouses, government agencies, and information retrieval services. Also included is a selected list of international sources. Each entry contains the name and address of the organization; a brief description of history, mission, and activities; and a list of publications or information retrieval services. Available without charge from: Arthritis Information Clearinghouse, P.L. Box 9782, Arlington, VA 22209; (703) 558-8250.

better. Miss Reid received \$2,000. The other winners were Cynthia A. Troue of Plainfield, IN, \$1,500; Dawn Adams, King City, MO, \$1,250; Lee Ann Blackmon, Albertville, AL, \$1,000; and Amanda Hetzel, Bluefield, WV, \$750.

Dr. Gay R. Anderson of Neenah, Wisconsin, was named "Physician of the Year." He is Medical Director of the Industrial Injury Clinic, Theda Clark Regional Medical Center in Neenah, and was honored for his outstanding contributions in advancing employment opportunities for disabled citizens. Anderson uses his skills as a board certified orthopedist and as a senior resident psychiatrist to help chronically injured workers return to work by evaluating their medical, social and psychological backgrounds. He continues to monitor their progress once back on the job.

Dr. Anderson plans and participates in an annual conference on rehabilitation of industrially injured workers which attracts other physicians, rehabilitation and insurance professionals, attorneys and employers from many states.

Two private employers were honored as "Employers of the Year" at the Conference. Ethicon, Incorporated of San Angelo, Texas, manufacturers of thread-like fastenings (sutures) used to close wounds and allied products, and Country Oven Bakery of Oakland, Maryland, were recognized for their efforts in hiring, training and promoting physically and mentally disabled people.

Ethicon received the Large Employer of the Year award (over 200 employees). In 1978, Ethicon began training the clients of Concho Valley Center for Human Advancement (CVCHA), a center for mentally retarded people. As a result of the training, 14 people with disabilities were placed in jobs at Ethicon, and recently CVCHA added additional equipment and another counselor to train more people.

The Country Oven Bakery received the Small (under 200 employees) Employer of the Year award. The bakery is a project of the Appalachian Parent Association Center to provide training and gainful, competitive employment for its clients. The Center provides social and vocational programs for disabled adults in Garrett County, Maryland. Prospective employees for the bakery are trained at the Center. The clients make up 77 percent of the bakery employees, and the program at the bakery has been observed by organizations from the U.S. and other countries.

Winners in the 1983 National Poster contest were: Chall Lucus of Washington, D.C. and Lori Steinkamp of Cincinnati, OH.

pared to perform the skills and tasks needed by business."

Projects With Industry received a strong vote of confidence with the recent signing of the "Emergency Jobs Bill" (P.L. 98-8) which provided PWI an additional \$5 million appropriation to train and place an estimated 5,000 disabled workers in competitive employment in fiscal year 1983.

PWI Development Manual Available from EIF

Begun four years ago, the Electronic Industries Foundation's Project With Industry is often cited as one of the best PWI programs. The project, which matches qualified disabled individuals to the vast manpower needs of the electronics industry, is now operational in seven areas and still expanding.

Because of its commitment to the objectives of PWI, and its desire to encourage further involvement by private enterprise toward these objectives, EIF, with a grant from the Department of Education's National Institute of Handicapped Research, has prepared a comprehensive resource manual entitled *A Creative Partnership: Guidelines for the Development of a Project With Industry*. The manual offers a "how to" approach which covers such areas and topics as: management systems and controls, evaluation and accountability, planning, marketing, and training.

The publication should serve as a valuable guideline for any organization or company wishing to start a PWI, but it will be of particular interest to national organizations—trade associations, industry groups, alliances of manufacturers and the like—which may benefit most from the planning, demonstration and experience of EIF.

The manual provides detailed information on all aspects of the EIF project, starting with the development of goals and objectives, and proceeding through organization of the advisory council, staffing the area office, project operations, data collection and reporting, and other elements of the model. The manual details **how** the various elements of the project were developed, the steps in the process, and the rationale behind them. It also presents samples of documents, forms, formats, job descriptions and other objective illustrations which may be duplicated.

Copies of the 102-page manual are available for \$14.50 from: Electronic Industries Foundation, 2001 Eye Street, N.W., Washington, D.C. 20006, (202) 457-4929.

REMINDER

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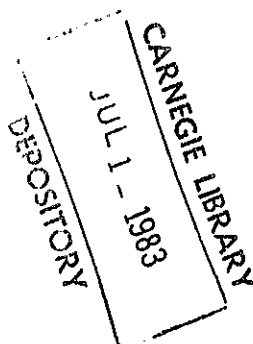
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